

NATIONAL ASSOCIATION OF PEOPLE WITH AIDS SUMMARY OF POLICY ON ASSISTED SUICIDE

- 0 While scientific and medical research have recently brought forward new treatment strategies and drugs that have significantly lowered the death rate in some populations, there is still no cure for AIDS and the long term **efficacy** of these regimens is undetermined.
- 0 The National Association of People with AIDS (NAPWA) believes all persons with terminal illness, including those with HIV disease, **are** entitled to a life of quality and happiness and should have the right to self-determination for all **end-**of-life decisions, including the right to die consistent with those ends. We support efforts to allow the terminally ill to seek assistance in dying from medical professionals.
 - o In order to protect those who may not have given full consideration to this important decision, we believe safeguards must be established which include the requirement of a dread disease diagnosis or **a** terminal prognosis by at least two physicians, an enduring request over a designated period of time (generally two weeks to one month), the right to rescind the request at any time, and clear penalties for coercion or abuse.
 - o *The New England Journal of Medicine* recently reported that 53 percent of **118** physicians treating AIDS cases in San Francisco responding to a survey conducted from November 1994 to January 1995 had assisted in a patient's death. This survey is important not only in that it reveals how widespread this practice has become, but also the increased acceptance by the medical community to provide care in partnership with the patient's wishes.



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**TESTIMONY OF
A. CORNELIUS BAKER
EXECUTIVE DIRECTOR**

**BEFORE
THE HOUSE COMMERCE COMMITTEE
SUBCOMMITTEE ON HEALTH & THE ENVIRONMENT
ON ASSISTED SUICIDE: LEGAL, MEDICAL, ETHICAL
AND SOCIAL ISSUES**

WASHINGTON, D.C.
MARCH 6, 1997

Mr. **Chairman** and members of the subcommittee, I thank you **for** affording the National Association of People with AIDS the opportunity to comment on this important issue

Introduction

In the United States over 600,000 have been reported as having AIDS, the late stage of disease resulting from infection with the human immunodeficiency virus (HIV). Of this number more than **half have died often** following prolonged periods of illness and painful deaths. It is estimated that there are more than **1** million people living with HIV and an additional 40,000 new infections each year. While scientific and medical research have recently brought forward new treatment

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strategies and drugs that have significantly lowered the death rate in some populations, there is still no cure for AIDS and the long term **efficacy** of these regimens is undetermined. The National Association of People with AIDS was founded in **1983** when a group of gay men diagnosed with a then new disease -- now known as AIDS -- came together in Denver, Colorado and developed a bill of rights to use in their fight **for** survival. These rights for people living with AIDS became known as The Denver Principles. For the last twelve years those principles have been the guiding light for the work **of** NAPVVA. Our organization serves **as** the national voice for people living with HIV disease in the United States. From advocacy on national legislation to the development of community prevention programs, NAPWA works on a range of activities to ensure that people living with HIV are participating and valued members in the quest to end this epidemic. We also provide our constituency with the resources and skills to deal with the medical, financial and social complexities of this disease.

NAPWA's basic mission is simple. We work everyday to guide the nation toward a moral agenda to save lives, support research for a cure and stop human suffering caused by the HIV epidemic.

For over a decade, it has **been the position of NAPWA that the** rights of people **with** AIDS include "to die and to LIVE in dignity." **This** position was expanded in 1995 to address issues related to **physician** assisted death.

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Policy on ~~Assisted~~ Doath

The National Association of People with AIDS (NAPWA) believes all persons with terminal illness, including those with HIV disease, are entitled to a life of quality and happiness and should have the right to self-determination for all end-of-life decisions, **including** the right to die consistent with those ends. While our goal is always to sustain and promote life, those with non-curable illnesses where pain management is not feasible or whom a physician finds is at the end of life expectancy with little possibility of medical intervention must be able to retain their dignity, integrity and self-respect. We support efforts to allow the terminally ill to seek assistance in dying from medical professionals.

NAPWA encourages all persons with HIV disease to seek assistance in establishing advance directives and living wills governing end of life decisions. Currently, honoring the refusal of treatments that a patient does not desire, that are disproportionately burdensome to the **patient**, or that will not **benefit** the person is ethically and legally permissible. Within this context, withholding or withdrawing life-sustaining therapies or risking the hastening of death through treatments aimed at alleviating suffering and/or controlling symptoms are ethically acceptable and do not constitute assisted death. Clearly, the ability to allow one's life to reach a natural conclusion without any medical intervention is **also** an acceptable **choice**.

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Conclusion

The promise of improved treatments and a cure for HIV and **AIDS seem** attainable for **the first** time in the history of the epidemic. We are all glad that improved access to health care and the new drug therapies for HIV and the opportunistic infections that ravage **the** bodies of those with late stage **disease** have **dramatically** reduced death rates in many parts of the United States. These events have not been universally **beneficial** for all people. There are, in fact, people like Charles Hall and his physician who have recently battled before the Florida Court in Palm Beach County for the right to **an** assisted suicide. Mr. Hall, who is very ill and has endured three bouts of an **AIDS-related** pneumonia simply wants the decision about when to end **his** life to be his.

The New England Journal of Medicine recently reported that **53** percent of 118 physicians treating AIDS cases **in** San Francisco responding to a survey conducted from **November 1994 to January 1995** had assisted in a patient's death. This survey is important not only **In** that it reveals how widespread this practice has become, but also the increased acceptance by the medical community to provide care in partnership with **ths** patient's wishes.

NAPWA believes that support of the patient is a humane response to the painful suffering that has been experienoed by far too many with HIV disease and other terminal illnesses. Indeed, what many patient's fear most is that they will be

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abandoned by their **physician** and other loved ones at the point of death, Having freely discussad this issue and prepared in advance is often freeing for **many** patients.

Studies of terminally ill patients have shown that those who have an open relationship with their physician or who have death inducing medication often do not exercise this option. We believe this is because the patient feels a greater degree of control and dignity

While we diligently work for a cure. we must also continue to support those who having come to the end of life seek to die a *good* and graceful death in the company of a Caring physician and love ones. The act of dying for a terminally ill person is a uniquely private and many times painful experience to which the government should not place additional burden or hardship. Restricting physician and other medical care that is federally supported would do so.

I look **forward** to working with the subcommittee on this challenging issue. NAPWA will be submitting additional comments and materials for your consideration at a later date.